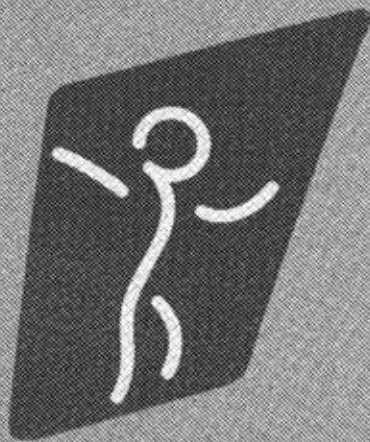


## **PSJ2 Exh 148**

# FINDING HELP FOR YOUR PAIN



A PAIN RESOURCE GUIDE  
AMERICAN PAIN FOUNDATION





# FIND THE PAIN

**I**f you are a person with serious chronic pain there's a good chance you've been going from one healthcare provider to another looking for relief. There's also a good chance you've heard the words, "Nothing more can be done to ease your pain" or "You'll just have to live with it."

**This resource guide is designed to encourage you to take charge of your pain** and to help you find a healthcare provider who has the know-how, skills, and willingness to work with you to manage it.

**Know the facts: more than 50 million Americans—men, women, and children—live with serious chronic pain that interferes with their personal, social, and work lives.** Although we now have the medical knowledge to manage most pain, most goes untreated, is undertreated, or is improperly treated.

# CARE YOU NEED

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**Why is finding a healthcare provider who is knowledgeable and skilled in pain management so difficult? Because understanding that chronic pain is a disease in itself—and one that is harmful to the body—is a new way of thinking.** Until recently, pain was considered only as a symptom of a disease or condition, or just a natural part of aging. So most healthcare providers have been trained in treating diseases—not pain.

**Today, we know that pain should never be ignored. It should be assessed thoroughly and treated aggressively, and in some cases managed as a chronic condition.** We've learned that when pain is managed, stress is reduced, and the body heals faster. We also know that when people with pain take an active role in their pain management, they get the best results possible: less pain and more involvement in life.

# GOOD PAIN MANAGEMENT BEGINS WITH YOU!

Your goal is to manage your pain and not let it manage you.

- **Get a correct diagnosis.** Your pain may or may not be signaling a disease or infection in your body.

- **Be in charge. Speak up! Be your own best advocate.** Understand that your pain needs to be assessed and treated because it can be very harmful to your body. Tell your healthcare provider you are in pain. Don't let anyone tell you your pain is "just in your head."

- **Realize that you are the expert on your pain.** Neither your healthcare provider nor anyone else can know how much you are hurting, where you are hurting, and how pain is interfering with your life.

- **Make a personal commitment to reducing your pain.** Be persistent. Start with determination and a positive outlook. Participate actively in your pain care all along the way—from finding a healthcare provider to developing and sticking with a pain management plan.

- **Do your homework!** Become informed and learn all you can about your health problem, your pain, pain management options, and the types of healthcare providers who specialize in pain. Use the tools and resources you would use to learn about anything else. Start by using the American Pain Foundation's (APF) publications and website ([www.painfoundation.org](http://www.painfoundation.org)). You can also visit your local library, search the Internet, and talk to people you know who are living

with pain. Reference librarians will often do Internet searches for you if you do not have a computer.

• **Learn to describe your pain symptoms clearly:** how much it hurts, where it hurts, how often it hurts, and what it feels like so you can contribute to the assessment of your pain. APF's pain assessment guide will help: [www.painfoundation.org/page.asp?menu=1&item=3&file=documents/doc\\_036.htm](http://www.painfoundation.org/page.asp?menu=1&item=3&file=documents/doc_036.htm)

• **Ask your healthcare provider if he or she is comfortable helping you manage your pain, and working as your partner in developing a pain management plan.** Make sure your healthcare provider:

- Knows about chronic pain and how to treat it.
- Believes your report of pain.
- Listens carefully to your concerns.
- Asks you questions and performs diagnostic tests to identify the problem.
- Encourages you to ask questions.
- Is comfortable when you disagree.
- Is willing to speak to your family or friends if you are not feeling well.
- Works with you to develop a pain management plan, including risks and benefits of each treatment.
- Tells you when he or she does not know something about your pain problem or treatment.



## LEARN ABOUT TREATMENT OPTIONS

There are many ways to treat pain. Find out about the benefits and risks of drug and non-drug therapies. Learn about the different ways drugs can be taken. For example, opioids—strong medications for relieving serious pain—can be delivered through pills, a transdermal patch, or a pump. Many non-drug therapies, used alone or in combination with medications, can also help reduce pain. A few include psychological counseling and physical therapy, as well as a host of complementary and alternative treatments such as massage, acupuncture, and yoga.

## WHEN SHOULD I SEE A PAIN CARE SPECIALIST?

Your family healthcare professional is trained to know about a wide range of diseases, but may not have had much training in treating pain. If your current treatment is not working or if your pain is getting worse, it's probably time to see a pain specialist.

## FIND A PAIN SPECIALIST

### START ASKING, START CALLING

Start by asking your provider to refer you to a specialist with expertise in treating your particular problem. A good question to ask is, "Who would you go to if you were in pain?" If he or she cannot suggest a specialist, the next step would be to check with your health insurance provider to see if there are pain specialists or pain clinics in your plan. You can also look for pain specialists by:



- Asking friends, family members, co-workers—particularly those who've had pain or know someone with pain—for suggestions.
- Speaking with people who belong to pain support groups in your area or region. Ask what doctors they like and why. Ask them what they look for in a specialist or pain center. Check with the American Chronic Pain Association: [ACPA@pacbell.net](mailto:ACPA@pacbell.net), [www.theacpa.org](http://www.theacpa.org), or 800-533-3231.
- Contacting the referral service of the largest hospital in your area.
- Calling state and county medical societies.
- Contacting your local chapter of the American Society of Pain Management Nurses (ASPMN), the American Pain Society (APS), and the American Academy of Pain Medicine (AAPM).
- Calling your local hospice. They can be helpful in finding a pain specialist even for non-end-of-life pain care. Also, someone in your State Cancer Pain Initiative may be able to suggest specialists even if your pain is caused by something other than cancer.

### NO PAIN SPECIALISTS IN YOUR AREA?

- Call or write your chamber of commerce and/or contact the board of directors (chairman or members) of your local hospital. Ask about a larger hospital offering outreach clinics or visiting physicians.
- Contact your local legislators about the lack of resources and request their assistance.



## LIMITED OR NO HEALTH INSURANCE?

- Contact your local hospital's social services department or your local health department.
- Contact Chronic Care Solutions, a nurse-run site focused on long-term care assistance: 2801 N. Glebe Road, Arlington, VA 22207, [www.chroniccaresolutions.com](http://www.chroniccaresolutions.com).
- Contact The Center for Patient Advocacy: 800-846-7444, [www.patientadvocacy.org](http://www.patientadvocacy.org).
- Contact the Patient Advocate Foundation: 800-532-5274.

## MAKE A LIST

Write down the names of the providers you think might be right for you. Leave room next to each doctor's name for notes and appointment times.

## CALL THE PAIN SPECIALISTS' OFFICES

Before contacting the doctor, talk with the office manager or a nurse at the practice. Begin by saying that you are looking for a doctor who can treat your pain. Describe your pain briefly. They will know about the types of cases the doctor handles.

Some questions to ask:

- Does the doctor treat my type of pain?
- Is he or she accepting new patients?
- How long will I have to wait to get an appointment?
- Will you accept my insurance?

- Is there a charge for an initial interview with the doctor?
- Are nurses involved in the practice and are they available to talk with me?
- Who will see me in case of an emergency?

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## INTERVIEW THE DOCTORS

As a self-advocate, it's up to you or someone helping you to interview the doctors on your list and determine who best suits your needs—that includes selecting someone who not only has the skills to treat you, but someone who makes you feel comfortable as well. Before going into the interview have all your questions written down. The interview will probably be no longer than 20 minutes. Get to the office early so that you can observe how the office works and how patients are treated. Do staff members and patients appear to be comfortable? Also, check the surroundings. Is the office clean? Is there adequate privacy?

Begin your interview by telling the doctor about your symptoms and all the medications you're taking. Describe other treatments for pain you've had. This interview will give you insight into the doctor's willingness and ability to communicate with you.

Some questions to ask the doctor:

- Have you treated others with my type of pain?
- What types of treatments do you use to treat my type of pain (medications and other therapies)?



- How would you describe good pain management?
- What is your success rate in treating my type of pain?
- How much relief should I expect from treatments?
- What do you think of complementary and alternative approaches (such as acupuncture, massage, hypnosis, herbal remedies)?

Other questions to ask:

- Are you a member of a pain specialty organization?
- What was the most recent pain conference or seminar you've attended?
- Do you do any teaching?
- Do you participate actively in improving pain management on a local, regional, or national level? If so, how?

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## CHECK THE DOCTORS' CREDENTIALS

Once you've selected one or more doctors, check them out by contacting your state or county medical society, the American Board of Medical Specialties ([www.abms.org](http://www.abms.org)), and the Specialty Licensing Board ([www.abms.org/member.asp](http://www.abms.org/member.asp)). You can also ask the doctor's office to supply his or her credentials concerning schooling and special training.

## SCHEDULE YOUR APPOINTMENT AND GET PREPARED

Once you've scheduled your appointment, gather your previous medical records and deliver these by hand to the doctor's office before the visit to make sure they are there for the doctor to review.

When you go in for your visit:

- Give the doctor a written description of your medical history, including all treatments for pain.
- Give the doctor a list of all medications you are taking including prescriptions, over-the-counter medications, and herbal supplements. Report any allergies.
- Discuss with your doctor what you expect from your treatment.
- Describe your goals. Ask the doctor to work with you to develop a pain management plan.
- Ask the doctor for a complete assessment of your pain.
- After the first visit, determine how satisfied you were with the visit. Did the doctor take enough time to answer all of your questions? Did he or she take time to ask you questions?
- If you were not satisfied with this visit for any reason, interview other doctors until you've found the right one.



## RESOURCES

### FIND A HEALTHCARE PROVIDER

- American Academy of Family Physicians  
[www.familydoctor.org](http://www.familydoctor.org)
- American Academy of Nurse Practitioners  
[www.aanp.org](http://www.aanp.org) 202-966-6414
- American Academy of Physician Assistants  
[www.aapa.org](http://www.aapa.org) 703-836-2272
- American Board of Medical Specialties  
[www.abms.org](http://www.abms.org) 847-491-9091
- American Medical Association  
[www.ama-assn.org](http://www.ama-assn.org) 312-464-5000
- Cancer Care  
[www.cancercare.org](http://www.cancercare.org) 800-813-4673
- Center for Patient Advocacy  
[www.patientadvocacy.org](http://www.patientadvocacy.org) 703-748-0400
- Doctor Directory  
[www.doctordirectory.com](http://www.doctordirectory.com) 828-255-0012
- Federation of State Medical Boards (disciplinary history of physicians)  
[www.docinfo.org](http://www.docinfo.org)
- Federation of State Medical Boards (verify physician credentials)  
[www.fsmb.org](http://www.fsmb.org) 817-571-2949
- National Conference of Gerontological Nurse Practitioners  
[www.ncgnp.org](http://www.ncgnp.org) 703-802-0088
- Nurse Practitioner Central  
[www.nurse.net/np](http://www.nurse.net/np) 202-659-2190
- Yellow Pages  
[www.yellowpages.com](http://www.yellowpages.com)

## Find A Pain Specialist OR CENTER

- American Alliance of Cancer Pain Initiatives (find listings of state initiatives)  
[www.aacpi.org](http://www.aacpi.org) 608-265-4013
- American Academy of Pain Medicine  
[www.painmed.org](http://www.painmed.org) 847-375-4731
- American Academy of Pain Management  
[www.aapainmanage.org](http://www.aapainmanage.org) 209-533-9744
- American Board of Pain Medicine  
 [www.abpm.org](http://www.abpm.org) 847-375-4726
- American Chronic Pain Association  
[www.theacpa.org](http://www.theacpa.org) 800-533-3231
- American Pain Society  
[www.ampainsoc.org](http://www.ampainsoc.org) 847-375-4715
- Cancer Care  
[www.cancercare.org](http://www.cancercare.org) 800-813-4673
- Case Management Resource Guide  
[www.cmrg.com](http://www.cmrg.com) 800-784-2332
- Commission on Accreditation of Rehabilitation Facilities  
[www.carf.org](http://www.carf.org) 520-325-1044
- Mayo Clinic Pain Management Center  
[www.mayoclinic.com/findinformation/conditioncenters](http://www.mayoclinic.com/findinformation/conditioncenters)
- National Hospice and Palliative Care Organization  
[www.nhpco.org](http://www.nhpco.org) 703-837-1500
- Pain.com  
 [www.pain.com/painclinics/default.cfm](http://www.pain.com/painclinics/default.cfm)



## NOTES

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. On the right side, there is a circular punch hole, likely for binding the paper into a notebook or folder. The paper appears slightly aged or off-white. There is no handwriting or other markings on the page.

# YOUR SUPPORT is NEEDED!

The American Pain Foundation, an independent, nonprofit 501(c)(3) organization, depends on unrestricted contributions and grants from individuals, foundations, and corporations. We would appreciate your support. Please send your tax-deductible donation to: **American Pain Foundation, 201 N. Charles St., Suite 710, Baltimore, MD 21201-4111.**

## Join Us

Help us build the pain movement and support for those with pain. It's free! Sign up to receive our newsletter, updates, legislative alerts, "information you can use," and more. Just complete and return this form.

☐ Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone \_\_\_\_\_ Fax \_\_\_\_\_

E-mail \_\_\_\_\_

- ☐ I am a Person with Pain
- ☐ Friend or Family Member
- ☐ Healthcare Professional
- ☐ Patient Advocate
- ☐ Member of the Media
- ☐ Corporate Representative
- ☐ Other
- ☐ I am interested in becoming a volunteer

☐ Mail to: American Pain Foundation  
201 N. Charles St., Suite 710  
Baltimore, MD 21201-4111  
Fax to: 410-385-1832  
Email: [info@painfoundation.org](mailto:info@painfoundation.org)

## ABOUT THE AMERICAN PAIN FOUNDATION:

The American Pain Foundation is an independent, nonprofit organization serving people with pain through information, advocacy, and support. Our mission is to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research on pain, and advocating to remove barriers and increase access to effective pain management.

For more information, visit our website:  
**[www.painfoundation.org](http://www.painfoundation.org)**. There you will find information about the causes of pain, different treatment options, ways to find trained specialists, peer support, and how to cope with pain. Our website also provides links to over 200 carefully selected websites on pain and related topics.

If you are unable to access the Internet and need more information, please write to us at

**American Pain Foundation  
201 N. Charles St., Suite 710  
Baltimore, MD 21201-4111**

To order this guide or for more information,  
leave a message on our toll-free line at  
**1-888-615-PAIN(7246)**

Or send an e-mail to  
**[info@painfoundation.org](mailto:info@painfoundation.org)**



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# READING This Could Help EASE YOUR PAIN

PAIN ACTION Guide

AMERICAN PAIN FOUNDATION



# How SERIOUS is THE PAIN Problem?

**M**ore than 70 million Americans suffer from chronic pain, and each year another 25 million experience acute pain from injuries or surgery. Although most pain can be greatly eased with proper pain management, most goes untreated, is under-treated, or is improperly treated. **No one should have to suffer needlessly when the knowledge and ability to manage most pain is available.**

Once your pain is under control, you'll be able to sleep better, focus on work, enjoy relationships with family and friends, and take part in social activities. Also, if your pain has been caused by an injury or surgery, your recovery may be faster.

**Finding good pain care and taking control of your pain can be hard work.** But the results are rewarding. Learn all you can about your pain and possible treatments. Work in partnership with your healthcare provider.

## NEW PAIN CARE STANDARDS FOR HEALTHCARE FACILITIES

**Most hospitals, nursing homes, and other healthcare facilities are now required to assess and treat pain. They are also required to inform patients about their right to effective pain care.** These new pain management standards were set by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).



## KNOW THE FACTS!

**Your pain may or may not be signaling a disease or infection.** Be sure to get a correct diagnosis.

**Pain is not something you "just have to live with."** Treatments are available to lessen most pain. Left untreated, pain can worsen other health problems, slow recovery, and interfere with healing. Get help right away. Don't let anyone tell you your pain is "just in your head."

**Not all healthcare providers know how to treat pain.** If your healthcare provider is unable to treat your pain effectively, ask him or her to refer you to a specialist. You may need to consider changing providers.

**Pain medications rarely cause addiction.** Morphine and similar pain medications, called opioids, can be highly effective for certain conditions. Unless you have a history of substance abuse, there is little risk of addiction when these medications are properly prescribed by a doctor and taken as directed. Physical dependence—which is not addiction—may occur and cause withdrawal symptoms if you stop taking these medications suddenly. You'll need to go off your medications gradually.

**Most side effects from opioid pain medications can be managed.** Nausea, drowsiness, itching, and most other side effects caused by morphine and similar opioid medications usually last only a few days. Constipation, the side effect that is most difficult to manage, can usually be relieved with laxatives, adequate fluid intake, and attention to diet.

**If you act quickly when pain starts, you can often prevent it from getting worse.** Take your medications when you first begin to experience pain. If your pain does get worse, talk with your healthcare provider. Your provider may safely prescribe higher doses or change the prescription. Non-drug therapies, such as relaxation training, can also help give you relief.





## PAIN CARE BILL OF RIGHTS

### AS A PERSON WITH PAIN, YOU HAVE THE RIGHT TO:

- Have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other healthcare professionals.
- Have your pain thoroughly assessed and promptly treated.
- Be informed by your healthcare provider about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.
- Participate actively in decisions about how to manage your pain.
- Have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- Be referred to a pain specialist if your pain persists.
- Get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

*Although not always required by law, these are the rights you should expect for your pain care.*

## How Do I Talk with My HEALTHCARE PROVIDER ABOUT MY PAIN?

**Speak up!** Tell your healthcare provider that you're in pain. It's not a sign of weakness to talk about your pain.

**Tell your healthcare provider where it hurts.** Do you have pain in one place or several places? Does the pain seem to move around?

**Describe how much your pain hurts.** Use a scale from 0 to 10: zero means no pain at all and 10 means the worst pain you can imagine. Explain when your pain is the highest, lowest, and how it is right now.

**Describe what makes your pain better or worse.** Is the pain always there? Does it go away? Does it get worse when you move in certain ways? Do other things make it better or worse?

**Describe what your pain feels like.** Use specific words like sharp, stabbing, dull, aching, burning, shock-like, tingling, throbbing, deep, or pressing.

**Explain how the pain affects your daily life.** Can you sleep? Work? Exercise? Participate in social activities? Concentrate? How does it affect your mood?

**Tell your healthcare provider about past treatments for pain.** Have you taken prescription medication or had surgery? Tried massage? Applied heat or cold? Exercised? Taken over-the-counter medications or vitamin supplements? Explain.

**Write down your questions for the doctor or nurse before an appointment.** Take notes at your visit. If possible, bring along a family member or friend for support.



## HOW CAN I GET THE BEST RESULTS POSSIBLE?

**Ask questions, and speak up if treatment isn't working.** Follow your pain management plan, ask questions, and speak up if you're not getting relief. Sometimes the plan needs to be changed. If necessary, seek other help. Be persistent.

**Set goals.** With your healthcare provider, set realistic goals for things you most want to do, such as sleeping, working, exercising, or enjoying sexual relations. Begin with the easiest goals first.

**Work with your healthcare provider to develop a pain management plan.** This might include a list of medications, when to take them, and possible side effects. It may include therapies other than medication, such as meditation. Make sure you understand the plan and carry it out fully. If you don't, you are less likely to get relief.

**Keep a pain diary.** Write about your level of pain at different times, how you're feeling, and what activities you can and cannot do. Keep a record of medications you're taking or any non-drug treatments. Bring the diary to your doctor visits.

**Ask your healthcare provider about non-drug, non-surgical treatments.** These could include relaxation therapy, exercise, massage, acupuncture, application of cold or heat, behavioral therapy, and other techniques.

**Ask your healthcare provider about ways to relax and cope with pain.** Your pain may feel worse if you're stressed, depressed, or anxious.

**If you have questions or concerns, speak up.** If you're worried about medications or other treatments, ask your healthcare provider. You have a right to know



how and why treatments work. The more you understand, the better you'll be able to participate in your plan.

**If you're having surgery, ask your healthcare provider for a complete pain management plan beforehand.** Don't wait until after surgery to ask about your pain care.

**If you're a patient in a hospital or other facility and you're in pain, speak up.** Ask a healthcare provider for help. If you don't get help right away, ask again. If you still don't get help, speak to a social worker or patient advocate. As of January 1, 2001, most hospitals and healthcare facilities are required to assess and treat your pain.

**Pace yourself.** Once you experience some degree of control over your pain, don't overdo it. Your body may be out of condition. Take time to gradually build up to normal activity.

**If you're not satisfied with your pain care, don't give up.** Does your healthcare provider listen to you? Is he or she able to assess and treat your pain? If after a reasonable time the answer is "no," ask for a referral to a pain specialist, or find another healthcare provider.

## How Should My PAIN BE TREATED?

**First, understand that your pain should be treated.** Left untreated, pain can be harmful to your body. Pain treatments vary for different conditions. Ask your healthcare provider to tell you about treatment options that can help manage the pain that comes with your particular condition. In addition, find out about ways to reduce stress and cope effectively with your pain.

Most often, people with moderate to severe chronic pain (pain that persists over time) get the very best results



with a combination of therapies that address the physical, functional, emotional, and spiritual aspects of pain.

**PAIN MEDICATIONS:** Medications, called analgesics, are valuable tools for reducing pain. Pain medications work best if taken before the pain becomes severe. You should take these medications when you begin to feel uncomfortable. Once pain becomes severe, it takes more time and more medication to bring it under control.

All medications, both over-the-counter and prescription, can have side effects. That's why it's important to take medications as directed and let your healthcare provider know about all of the medications you are taking (see Guidelines below).

**Acetaminophen is a basic pain reliever that can be bought over-the-counter.** Acetaminophen is often effective in managing mild pain. When taken as directed it is usually safe. If taken for an extended period, your healthcare provider should be aware and may want to monitor you for stomach, liver, and/or kidney problems. Acetaminophen comes as tablets and rectal suppositories.

**Nonsteroidal anti-inflammatory drugs (NSAIDs) are pain relievers that are available over-the-counter (such as aspirin, ibuprofen, and naproxen sodium) and by prescription.** NSAIDs are stronger than acetaminophen and are often used to treat mild to moderate pain. Cox-II inhibitors (such as rofecoxib and celecoxib) are new forms of NSAIDs. These drugs may be easier on the stomach and cause less bleeding problems than standard NSAIDs. However, they may not be safe for some people with heart disease or those allergic to sulfa. Most NSAIDs are available in pill form.

*The drugs above are associated with liver damage, especially when used with alcohol or taken over a long period. NSAIDs can affect the kidneys and promote bleeding. They also have a "ceiling effect"—after the maximum dose is reached, there is no additional pain relief.*

**Opioids are strong medications used to relieve moderate to severe pain.** Available only by prescription, opioids come in a variety of dosing forms and are sometimes combined with other substances such as aspirin and acetaminophen. Some opioids are given in pill form. Medications such as morphine and fentanyl can also be given through a transdermal skin patch (fentanyl only), injections into the veins or tissue, or under the skin into the muscle. Opioids can also be given under the tongue, through rectal suppositories, or in some cases, injected into the epidural or spinal space. **Short-acting oral opioids**, such as Oxycodone and hydromorphone, provide 4 to 6 hours of pain relief and are often used for breakthrough pain—short episodes in which pain increases dramatically. **Long acting opioids** usually last longer (8 hours to 3 days), and are used for moderate to severe pain states, such as lower back pain, osteoarthritis, and cancer.

More information on opioids can be found on the APF website: [www.painfoundation.org](http://www.painfoundation.org)

**OTHER PAIN MEDICATIONS:** Some medications that were developed to treat other conditions (such as anti-depressants, anti-inflammatory steroids, and anticonvulsants) can be helpful for treating pain. They are often given in combination with other analgesics. Discuss any questions you have about these drugs with your health-care provider and your pharmacist.

Topical medicines (applied to skin), like creams that contain anesthetics (numbing medicine) or capsaicin (made from hot peppers), may relieve pain on the surface level.

**NON-INVASIVE, NON-DRUG THERAPIES:** There are many non-drug therapies for relieving pain. They can be used alone or in combination with drug therapies:

**Thermal treatments**, such as applying heat (heating pad) and/or cold (ice pack), can reduce pain by allowing “non-pain” sensations to overload the nervous system.



**Professional therapeutic massage** is a method of manipulating the soft tissues of the body to relieve pain, release tension, and restore function. Often, balms or lotions are used with massage to increase relief of pain that is caused by tension, spasms, or painful areas called "trigger points."

**Physical therapy**, which can help improve function and quality of life, often includes: manual therapy techniques; exercises to improve strength and balance; use of physical agents such as ultrasound or electrical stimulation; and functional training.

**Chiropractic** is a system of adjusting segments of the spine to remove nerve interference. Chiropractors may also use other therapies, such as lifestyle and nutrition counseling.

**Psychological counseling/cognitive therapy** offers people powerful skills to help them manage their pain and stress.

**Mind/body techniques** are based on the idea that the mind and body work together as a unit. Mind/body techniques can relieve pain by reducing stress (which helps the immune system). Mind/body techniques include biofeedback, hypnosis, yoga, guided imagery, prayer and meditation, and music and humor therapy. These therapies help disengage consciousness.

**Acupuncture** is one of the oldest therapies known to mankind, and involves the insertion of very fine metal needles into the skin at specially designated points of the body. Acupuncture is thought to work by altering the body's energy flow and allowing the body to regain its balance and heal itself.

**INVASIVE PAIN THERAPIES:** These are methods recommended for chronic or combined pain problems. Healthcare providers with special training in pain management can evaluate whether these methods could



improve your pain relief and give you information about what you can expect.

**Analgesia catheters and infusion pumps** deliver drugs such as opioids, anesthetics (numbing agents), and muscle relaxants. Catheters are placed in a variety of locations of the body. Sometimes they are used for a short period of time (for acute pain after surgery), or they can be surgically implanted for complex pain (cancer pain or nerve pain). An analgesia pump may be connected to the catheter and worn outside the body (short-term) or surgically placed inside the body (long-term). Special training is required for pain physicians and nurses offering these therapies.

**Injection therapies** may be used for pain located in a specific area of the body. Injecting medication to numb and stop inflammation may reduce the number of pain signals. These "nerve blocks" may give short or long-term relief, depending on the pain problem and your unique response. A physician requires special training to perform these injections.

**Chemical, thermal, or surgical ablation** may be used for some complex nerve pain problems. These methods destroy nerves that sense pain and other feelings (such as touch or pressure) without involving nerves used for movement and strength. Strong chemicals like phenol or alcohol may be used. Extreme temperatures from freezing (called cryoanalgesia) or heat (radiofrequency) may be recommended. Surgery may be used to either permanently cut the nerve area or remove the suspected cause of pain (spinal disc, tumor, etc.). For some people, surgery may provide complete and permanent relief, while for others the relief may be temporary or partial.

**Spinal cord stimulators (SCS) or dorsal column stimulators (DCS)** may be inserted for some special nerve pain problems. An electrode (metal wire) is placed around the spinal nerves that are receiving pain

messages. A small transmitter is programmed to send signals that block pain messages before they enter the spinal cord (where pain messages go before traveling to the brain for recognition). This transmitter can be worn on your clothing. Physicians who insert and manage this therapy require special training.

**Radiation** may be recommended if pain is caused by a tumor. This therapy helps to shrink the tumor size that may be pressing on nerves. Special radiation therapies may also be used to lessen bone pain.

### GUIDELINES FOR TAKING MEDICATIONS

**Tell your healthcare provider about all the medications you are taking—both prescription and over-the-counter. Include vitamins and herbal supplements.** Medications and herbs can interact with each other and cause side effects or complications. In some cases, some combinations of medications can either reduce or increase the effects of other needed medications. For more information, see the National Council on Patient Information and Education (NCPPIE) website at [www.medicare.gov](http://www.medicare.gov).

**Talk to your healthcare provider about any food or medication allergies you may have.** This information can help determine your treatment.

**Take all medications as directed.** Even common, over-the-counter medications can have side effects—particularly if not taken as directed.

**Talk to your pharmacist about your medications and how different foods might interfere with how they work.**

*Caution: alcohol, in combination with many pain medications, can be very dangerous. If you drink, even socially, let your healthcare provider know.*



## WHERE CAN I FIND HELP?

- Start at APF: [www.painfoundation.org](http://www.painfoundation.org), toll-free 888-615-PAIN.

### If YOU WANT TO FIND A PAIN SPECIALIST:

- Ask your healthcare provider for a referral to a pain specialist or pain clinic.
- Ask family, friends, and co-workers who have had pain.
- Contact the referral service of the largest hospital in your area.
- Call your state and county medical societies.
- If you are in a managed care program, call your representative and get the list of approved pain specialists.
- Your local hospice can often suggest pain specialists.

### ADDITIONAL RESOURCES

- American Alliance of Cancer Pain Initiatives [www.aacpi.wisc.edu](http://www.aacpi.wisc.edu)  
608-265-4013
- American Academy of Pain Medicine [www.painmed.org](http://www.painmed.org)  
847-375-473
- American Academy of Pain Management [www.aapainmanage.org](http://www.aapainmanage.org)  
209-533-9744
- American Board of Pain Medicine [www.abpm.org](http://www.abpm.org)  
847-375-4726
- American Chronic Pain Association [www.theacpa.org](http://www.theacpa.org)  
800-533-3231
- American Pain Society [www.ampainsoc.org](http://www.ampainsoc.org)  
847-375-4715
- Cancer Care [www.cancercare.org](http://www.cancercare.org)  
800-813-4673
- Case Management Resource Guide [www.cmrg.com](http://www.cmrg.com)  
800-784-2332
- Mayo Clinic Pain Management Center [www.mayoclinic.com](http://www.mayoclinic.com)
- National Hospice and Palliative Care Organization [www.nhpc.org](http://www.nhpc.org)  
703-837-1500
- Pain.com [www.pain.com](http://www.pain.com)

### To Find Support

- APF's PainAid [painaid.painfoundation.org](http://painaid.painfoundation.org)
- American Chronic Pain Association [www.theacpa.org](http://www.theacpa.org)  
916-632-0922



## YOUR SUPPORT is NEEDED!

The American Pain Foundation, an independent, nonprofit 501(c)(3) organization, depends on unrestricted contributions and grants from individuals, foundations, and corporations. We would appreciate your support. Please send your tax-deductible donation to: American Pain Foundation, 201 N. Charles St., Suite 710, Baltimore, MD 21201-4111.

## Join Us

Help us build the pain movement and support those with pain. It's free! Sign up to receive our newsletter, e-newsletter, legislative alerts, and more. Just complete and return this form.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_  Zip \_\_\_\_\_

Telephone \_\_\_\_\_  Fax \_\_\_\_\_

E-mail \_\_\_\_\_

- ☐ I am a Person with Pain
- ☐ Friend or Family Member
- ☐ Healthcare Professional
- ☐ Patient Advocate
- ☐ Member of the Media
- ☐ Corporate Representative
- ☐ Other
- ☐ I am interested in becoming a volunteer

Mail to: American Pain Foundation  
201 N. Charles St., Suite 710  
Baltimore, MD 21201-4111  
Fax to: 410-385-1832  
Email: [info@painfoundation.org](mailto:info@painfoundation.org)

## ABOUT THE AMERICAN PAIN FOUNDATION:

The American Pain Foundation is an independent, nonprofit organization serving people with pain through information, advocacy, and support. Our mission is to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research on pain, and advocating to remove barriers and increase access to effective pain management.

For more information, visit our website: [www.painfoundation.org](http://www.painfoundation.org). There you will find information about the causes of pain, different treatment options, ways to find trained specialists, peer support, and how to cope with pain. Our website also links to over 200 carefully selected websites on pain and related topics.

If you are unable to access the Internet and need more information, please write to us at:

**American Pain Foundation  
201 N. Charles St., Suite 710  
Baltimore, MD 21201-4111**

To order this guide or for more information,  
leave a message on our toll-free line at:  
**1-888-615-PAIN(7246)**

Or send an email to:  
**[info@painfoundation.org](mailto:info@painfoundation.org)**



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## PAIN CARE BILL OF RIGHTS

### AS A PERSON WITH PAIN, YOU HAVE THE RIGHT TO:

- have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other healthcare professionals.
- have your pain thoroughly assessed and promptly treated.
- be informed by your healthcare provider about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.
- participate actively in decisions about how to manage your pain.
- have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- be referred to a pain specialist if your pain persists.
- get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

*Although not always required by law, these are the rights you should expect for your pain care.*



## How do I talk with my HEALTHCARE PROVIDER ABOUT PAIN?

- Speak up! Tell your healthcare provider that you're in pain.
- Tell your doctor or nurse where it hurts. Do you have pain in one place or several places? Does the pain seem to move around?
- Describe how much your pain hurts. On a scale from 0 to 10, zero means no pain at all and 10 means the worst pain you can imagine.
- Describe what makes your pain better or worse. Is the pain always there, or does it go away sometimes? Does the pain get worse when you move in certain ways? Do other things make it better or worse?
- Describe what your pain feels like. Use specific words like sharp, stabbing, dull, aching, burning, shock-like, tingling, throbbing, deep, or pressing.
- Explain how the pain affects your daily life. Can you sleep? Work? Exercise? Participate in social activities? Concentrate? How is your mood?
- Tell your healthcare provider about past treatments for pain. Have you taken medication or had surgery? Tried massage or meditation? Applied heat or cold? Exercised? Explain what worked and what didn't.

American Pain Foundation  
201 N. Charles Street, Suite 710  
Baltimore, MD 21201-4111

Toll-free information line: 888-615-7246

[www.painfoundation.org](http://www.painfoundation.org)



## DERECHOS PARA TRATAMIENTO DE DOLOR

### COMO PERSONA CON DOLOR, USTED TIENE EL DERECHO DE:

• tener su informe de dolor tratado en serio y con dignidad y respeto por doctores, enfermeras, farmacéuticos, y otros profesionales en trato de salud.

- tener su dolor completamente considerado y tratado enseguida.
- ser informado por su doctor acerca de la causa mas probable de su dolor, tratamientos posibles, y los beneficios, los riesgos, y el costo de cada uno.
- participar activamente en decisiones acerca de la manera de controlar su dolor.
- tener su dolor evaluado de nuevo regularmente y su tratamiento cambiado si su dolor no ha disminuido.
- ser referido a un especialista en tratamiento de dolor si continua su dolor.
- recibir respuestas claras e inmediatas a sus preguntas, de tener tiempo para hacer sus decisiones, y de rehusar cierto tipo de tratamiento si usted desea.

*Aunque no siempre exigidos por la ley, estos son derechos que deben ser esperados, y si necesario, exigirlos para tratamiento de su dolor.*



## ¿COMO HABLO CON MI DOCTOR, ENFERMERA, O TRABAJADORA SOCIAL DE MI DOLOR?

- Dejese escuchar! Digale a su doctor, enfermera, o trabajadora social que tiene dolor.
- Digale a su doctor, enfermera, or trabajadora social donde le duele. ¿Tiene dolor en un lugar o en diferentes lugares? ¿Tiene dolor que parece moverse de un lado a otro?
- Describa la intensidad de su dolor. En la escala de 0 a 10, 0 significa que no hay dolor ninguno, y 10 significa que es el peor dolor que usted pueda imaginar.
- Describa lo que hace que su dolor mejore o empeore. ¿Si el dolor siempre está presente o si se va algunas veces? ¿Si el dolor se empeora cuando se mueve de cierta manera? ¿Si hay otras cosas que hacen que su dolor mejore o empeore?
- Describa como usted siente el dolor, si es agudo, doloroso, ardiente, profunda sensación de hormigueo, de latidos de presión . . .
- Explique como el dolor afecta su vida diaria. ¿Puede dormir? ¿Trabajar? ¿Hacer ejercicios? ¿Participar en actividades sociales? ¿Concentrar? ¿Como está su humor?
- Digale a su doctor, enfermera, o trabajadora social de tratamientos anteriores que a tenido para su dolor. ¿Si a tomado medicamento o tenido alguna operación? ¿Si ha tratado masaje o meditación? ¿Aplicado calor o frio? ¿Ejercicio? Explique lo que le funcionó o no le funcionó.

American Pain Foundation  
201 N. Charles Street, Suite 710  
Baltimore, MD 21201-4111

[www.painfoundation.org](http://www.painfoundation.org)

Distribution



***American Pain Foundation  
Power Over Pain (POP)***

**Initial Distribution Form**

**Send 5 (five) POP Start-Up Packs to each POP State which include:**

- ☐ **POP Community Action Kit**
- ☐ **POP Community Action Kit/CD**
- ☐ **POP Power Pack-Public Awareness Conversation Kit which includes:**
  - POP PowerPoint Presentation for --Public Audience/CD
  - POP PowerPoint Presentation for Professional Audience/CD
  - POP Fact Sheet
  - Presentation Objectives and Evaluation Tool for Continuing Education (CE) Application
- ☐ **A Sample of each APF publication which includes:**
  - Pain Action Guide
  - Finding Help Brochure
  - Pain Bill of Rights-English
  - Pain Bill of Rights-Spanish
  - Pain Poster
  - Pain Community News-"Best of"
  - Pain Community News- most recent version
  - APF Order Form
- ☐ **POP Pin (1,000 per bag)**

**Name:**

**Date:**

**Title:**

**Organization:**

**Delivery Address:**

**City:**

**State:**

**Zip:**

**Phone:**

**Fax:**

**Email:**

**For Office Use:    Delivery Method:**

**Notes:**

**8/13/04 cn**

[illegible]





**AMERICAN PAIN FOUNDATION**

*A Consumer Information, Education and Advocacy Organization  
Helping People Who Suffer From Pain*

Phone: 410-783-7292, x226

Fax: 410-385-1832

**To:** Patrick Milmoie, Canastota Pub. Co., Inc      **From:** Carolyn Nuth

**Fax:** 315-697-8496

**Pages:** 2 , including cover

**Phone:** 315-697-9010

**Date:** 8/13/04

● Please send same order to all three addresses:

- 1000      Pain Action Guide/Reading this could...
- 1000      Finding Help brochure
- 1000      Pain Care Bill of Rights Card- English
- 1000      Best Of Newsletters
- 100 \*      Pain Care Bill of Rights POSTER (only 100)\*

**Please send materials as directed on Page 2. Call if you have any questions.  
Thank you, Carolyn Nuth, Tel: 410-783-7292, x222 (Lisa Nuth)**

*If there are any problems or questions regarding the **transmission**  
of this fax please call us at (410) 783-7292, x226*

American Pain Foundation  
201 N. Charles Street, Suite 710  
Baltimore, MD 21201  
[www.painfoundation.org](http://www.painfoundation.org)

September 30, 2004



**AMERICAN PAIN FOUNDATION**

American Pain Foundation, Inc.  
201 North Charles Street, Suite 710  
Baltimore, MD 21201  
410-783-7292, x226  
Fax (410) 385-1832  
[www.painfoundation.org](http://www.painfoundation.org)

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**SEND MATERIALS TO:**

Patricia Trotta, RN, MSN (Tel: 203-379-4763)  
Program Manager, New England Pain Initiatives  
American Cancer Society, New England Division  
538 Preston Avenue  
Meriden, CT 06450-1004

Stacie Ogborn (Tel: 316-263-6380)  
Kansas LIFE Project  
Project Operations Manager  
1901 University  
Wichita, KS 67213

Judith D. Murphy, EdD, CHES (Tel: 866-466-0626)  
Regional Coord for New England Pain Relief Program  
American Cancer Society, New England Division, Inc.  
121 Connor Way, Suite 240  
PO Box 1460  
Williston, VT 05495





## **Power Over Pain (POP): Material Distribution Plan**

### ***Recommended Distribution Process:***

- o PIC staff (Carolyn or designee) receives all orders for materials:
  - o All POP-state requests should be directed to Public Outreach Manager
    - New start-up orders and,
    - Additional requests for materials
  - o Once requests are approved by the Public Outreach Manager, they will be forwarded to PIC for distribution.
  - o All individual requests will be handled by PIC staff.
- o PIC staff enters all completed orders into database for tracking.
- o APF team will be able to view status and create reports via database program.

### ***Needs To Be Created or Determined:***

- o Revision of new general order form, to include
  - o Pricing options for bulk orders on both order forms
  - o Power Pack
  - o POP pins
  - o POP T-shirts
- o Discount order form for POP states
- o Cost of Power Pack: \$20.00
- o Cost of POP Pin: 35 cents each/ \$275/per 1000
- o Cost of individual PowerPoint CD-R: \$10.00
- o Re-visit purchase price of start up pack
- o POP T-shirts w/state name on back: ???



## **Power Over Pain (POP): Material Distribution Plan**

### **Materials:**

#### APF Start-up Pack Includes:

- POP Community Action Kit
- POP Community Action Kit CD-R
- Power "Pack"= Public Awareness Conversation Kit
  - POP PowerPoint Presentation for Public Audience CD-R
  - POP PowerPoint Presentation for Professional Audience CD-R
  - POP Fact Sheet
  - Presentation Objectives and Evaluation Tool for Continuing Education (CE) Application
- Sample of each APF publications:
  - Pain Action Guide
  - Finding Help Brochure
  - Pain Bill of Rights-English
  - Pain Bill of Rights-Spanish
  - Pain Poster
  - Pain Community News-"Best of"
  - Pain Community News- most recent version
- POP pin

#### Separate mailing of AACPI publication from AACPI office:

- Cancer Pain Can Be Relieved

#### Additional distribution:

#### **POP Funded States:**

- A total of 5 copies of POP Start-up pack
- Bulk mailings of APF publications up to a total of 10,000 of each piece:
  - 1,000 pieces for initial start-up of POP activities
  - Staged mailings of additional pieces dependant on planned POP projects.
- \*\*Note: POP Action Kits or Power Pack items are not included with these publications.
- After the first 10,000 pieces, subsequent material requests may be purchased at 50% discount.
- A total of up to 500 of the AACPI's "Cancer Pain Can Be Relieved" patient educational booklet, as requested.

#### **Non-POP Funded States or other individual requests:**

- May purchase POP Start up Pack at full purchase price
- Standard order form for materials will be included



STATES